

# Congress 2026 patient priorities survey

A report on the results



## **Introduction**

In July and August 2025, ELF circulated a survey to members of the ELF Patient Organisation Network - a group made up primarily of patients, patient organisation representatives and caregivers.

The survey invited respondents to identify their priorities for scientific sessions at the ERS Congress 2026, which will have the theme 'United for Better Breathing: Partnership Between Patients, Clinicians and Researchers'. Participants were first asked to share their priorities for general lung health, followed by their priorities within specific disease areas of interest.

## **Results**

A total of 65 completed responses were received.

### **Priority topics for general lung health**

Responses to this question can be grouped into 10 overarching topic areas. Table 1 on the following page presents these topics, the frequency with which each was mentioned, and a summary of the main comments under each theme.

**Table 1: Priority topics for general lung health**

<b>Overarching theme</b>	<b>No. of times mentioned</b>	<b>Main topics in each theme</b>
<b>Patient Partnership and Communication</b>	24	<ul style="list-style-type: none"><li>• Co-creation of care and research: patients as equal partners</li><li>• Shared decision-making, patient-clinician communication, and plain-language explanations</li><li>• Recognition of patient lived experience as expertise</li><li>• Including patients in research design, working groups, and decision-making structures</li><li>• “Nothing about us without us”</li></ul>
<b>Environmental and Societal Factors</b>	22	<ul style="list-style-type: none"><li>• Air pollution, smoking, vaping, and clean air campaigns</li><li>• Inside air quality (household, workplace exposures, infections)</li><li>• Impact of climate change on lung health</li><li>• Societal challenges: stigma of lung disease, public misunderstanding of fatigue and disability</li></ul>
<b>Innovation, Technology, and Research</b>	21	<ul style="list-style-type: none"><li>• Digital tools to empower patients (home as “everyday hospital”)</li><li>• Use of AI in screening and care prediction</li><li>• Lung regeneration, microbiome/gut–lung axis research</li><li>• Greater inclusion of patients in co-creating and disseminating research outcomes</li><li>• PROMs integrated into both research and care</li></ul>
<b>Rehabilitation and Self-Management</b>	19	<ul style="list-style-type: none"><li>• Benefits of pulmonary rehabilitation and exercise</li><li>• Self-management: singing exercises, nutrition, hydration</li><li>• Value of non-medical interventions in quality of life</li><li>• Digital tools and education to empower patients and caregivers</li></ul>

<b>Cross-cutting Symptoms and Comorbidities</b>	18	<ul style="list-style-type: none"> <li>• Symptom-focused care: breathlessness, fatigue, multimorbidity</li> <li>• Priorities: sleep problems, pain management, post-COVID conditions, rare lung diseases</li> <li>• Case-based learning: clinicians and patients presenting together</li> <li>• Interplay of lung conditions with heart disease, infections, and aging</li> </ul>
<b>Access and Equity Challenges</b>	13	<ul style="list-style-type: none"> <li>• Access to treatments and care inequality across regions/countries</li> <li>• Cost/affordability of drugs and insurance</li> <li>• Shortages of specialists and long waiting times</li> <li>• Faster regulatory approvals and improved primary-care respiratory support</li> </ul>
<b>Mental Health and Emotional Wellbeing</b>	13	<ul style="list-style-type: none"> <li>• Anxiety, depression, fear of breathlessness, stigma, and reduced quality of life as “invisible burdens.”</li> <li>• Integrating psychological support in routine respiratory care</li> <li>• Recognition of the trauma of chronic untreatable disease.</li> </ul>
<b>Holistic and Multidisciplinary Care</b>	12	<ul style="list-style-type: none"> <li>• Focus on the whole person – mental, physical, social</li> <li>• Joined-up care across multiple conditions and medical specialties</li> <li>• Recognising carers’ perspectives</li> <li>• Holistic treatment as a complement, not replacement to medication</li> </ul>
<b>Treatments and Safety</b>	11	<ul style="list-style-type: none"> <li>• Access, affordability, and side effects of new drugs</li> <li>• Adherence and compliance challenges in chronic lung conditions</li> <li>• Antimicrobial resistance (AMR) and alternative therapies such as bacteriophage</li> <li>• Bolder funding and innovation</li> </ul>
<b>Early Diagnosis and Biomarkers</b>	10	<ul style="list-style-type: none"> <li>• Early detection and better screening</li> <li>• Genetics, epigenetics, and biomarkers of lung disease</li> <li>• Risk stratification and environmental triggers</li> <li>• More modern tools for monitoring and early-warning systems</li> </ul>

## Priority topics for specific lung diseases

Respondents outlined condition-specific topics for 11 different lung diseases. Table 2 below gives a summary of the priorities mentioned.

<b>Table 2: condition-specific topics</b>	
<b>Lung condition</b>	<b>Topics suggested</b>
Aspergillosis	<ul style="list-style-type: none"> <li>• Concerns about air quality and when to stay indoors</li> <li>• Interest in new drugs for bronchiectasis and early disease predictors</li> <li>• Issues of co-morbidity and medication side effects</li> <li>• Emphasis on holistic health and patient-centred care</li> <li>• Highlight on neglected indoor air quality (NTM) and prevention education</li> <li>• Inclusion of patient partners and therapeutic patient education</li> </ul>
Asthma	<ul style="list-style-type: none"> <li>• Severe allergic asthma is under-researched compared to eosinophilic asthma</li> <li>• Co-morbidity concerns</li> <li>• Recovery from exacerbations and related harm</li> <li>• Fatigue and mobility impacts</li> <li>• Breathing techniques</li> <li>• Availability of new treatments</li> </ul>
Bronchiectasis	<ul style="list-style-type: none"> <li>• New research</li> <li>• Self-help measures</li> <li>• Post-nasal drip</li> <li>• Medication for inflammation and new drug options</li> <li>• Issues with resistant antibiotics</li> <li>• Airway clearance technique adherence and awareness</li> <li>• Need for broader medical awareness and education</li> <li>• Exacerbations and impact on quality of life</li> <li>• Use of information from patients who have improved</li> <li>• Blood in sputum: meaning and implications</li> <li>• Access to new medications and mucolytics</li> <li>• Diagnostic delays</li> <li>• Lung microbiome research</li> <li>• Autoimmune diseases related to bronchiectasis</li> <li>• Fatigue post-infection, why it happens and how to manage</li> <li>• Need for GP awareness regarding topics such as chest clearance and physiotherapy</li> <li>• Patient concern about exacerbations and their triggers</li> <li>• Infection treatment without antibiotics</li> </ul>

Chronic cough	<ul style="list-style-type: none"> <li>• Advances in research, such as the mechanism of cough</li> <li>• New treatments</li> <li>• Lack of awareness amongst pulmonologists</li> </ul>
COPD	<ul style="list-style-type: none"> <li>• Importance of correct diagnosis and avoiding delay</li> <li>• Improving support and signposting</li> <li>• Upskilling GPs about antibiotics and biofilm-related antibiotic resistance</li> <li>• Confusion around antibiotic resistance leading to delayed treatments</li> <li>• Concern about Serratia Marcescens in the home/environment.</li> <li>• Issues with biofilm bacteria and persistent infection</li> <li>• Pathways to oxygen prescription</li> <li>• Supporting patients and addressing patient fears</li> </ul>
Cystic fibrosis	<ul style="list-style-type: none"> <li>• Phage therapy as a complement to antibiotics.</li> <li>• Side effects and nutritional interactions with Kaftrio</li> </ul>
NTM pulmonary disease	<ul style="list-style-type: none"> <li>• Overlap with COPD, bronchiectasis and cystic fibrosis</li> <li>• Need for recognition and standard care</li> <li>• Making NTM PD visible and included in disease lists</li> </ul>
Pulmonary fibrosis	<ul style="list-style-type: none"> <li>• Prevention, early diagnosis, and early treatment</li> <li>• Lung transplantation for IPF</li> <li>• Connection between IPF and cancer; advances in treatment</li> <li>• Improving quality of life for familial pulmonary fibrosis</li> <li>• Lack of recognition</li> <li>• Effects of exacerbation and recovery</li> <li>• Clinical findings and impact on guidelines/treatments.</li> <li>• Progressive fibrosing diseases: research and treatment</li> <li>• Patient-centred, multidisciplinary care, rehabilitation, and palliative support</li> <li>• PF's prognosis</li> <li>• Decision-making around antifibrotic medication</li> </ul>
Pulmonary hypertension (PH)	<ul style="list-style-type: none"> <li>• Importance of patient-reported outcomes in care and drug development</li> <li>• Consideration of lung transplantation</li> </ul>
Sarcoidosis	<ul style="list-style-type: none"> <li>• Sleep disturbances as a symptom</li> <li>• Impact of clinical findings on care guidelines</li> <li>• Importance of multidisciplinary care</li> <li>• New medications and their side effects</li> <li>• Growing impact of sarcoidosis</li> </ul>

Sleep and breathing disorders	<ul style="list-style-type: none"><li>• Use of telehealth</li><li>• Safe breathing exercises</li><li>• Research into treatments beyond CPAP</li><li>• Waiting times and access to treatment</li></ul>
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